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“Missing Pieces” – Functional, Social, and Environmental Barriers to Recovery for Vulnerable Older Adults Transitioning From Hospital to Home

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Abstract

Background—Recent interventions to improve transitions in care for older adults focus on hospital discharge processes. Limited data exists on patient concerns for care at home after discharge, particularly for vulnerable older adults.

Design—We used in-depth, in-person interviews to describe barriers to recovery at home after leaving the hospital for vulnerable, older adults. We purposefully sampled by age, gender, race, and English proficiency to ensure a wide breadth of experiences. Interviews were independently coded by two investigators using the constant comparative method. Thematic analysis was

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D.H. Cheung: data acquisition (interviews), data interpretation; manuscript revision; final approval for publication.

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performed by the entire research team with diverse backgrounds in primary care, hospital medicine, geriatrics, and nursing.

Setting and Participants—We interviewed vulnerable older adults (low income/health literacy, and/or Limited English Proficiency) who were enrolled in a larger discharge interventional study within 30 days of discharge from an urban public hospital. All participants were interviewed in their native language (English, Spanish, or Chinese).

Results—We interviewed 24 patients: mean age 63 (55–84), 66% male, 67% Non-white, 16% Spanish-speaking, 16% Chinese-speaking. We identified an overarching theme of “missing pieces” in the plan for post-discharge recovery at home from which three specific sub-themes emerged: (1) functional limitations and difficulty with mobility and self-care tasks; (2) social isolation and lack of support from family and friends; (3) challenges from poverty and the built environment at home. In contrast, patients described mostly supportive experiences with traditional focuses of transition care such as following prescribed medication and diet regimens.

Conclusion—Hospital-based discharge interventions that focus on traditional aspects of care may overlook social and functional gaps in post-discharge care at home for vulnerable older adults. Post-discharge interventions that address these challenges may be necessary to reduce readmissions in this population.

Keywords

Transitions of care; discharge care; vulnerable seniors; qualitative methods

INTRODUCTION

Transitions from hospital to home present many challenges for older adults which can contribute to fragmented care, adverse drug events, and readmissions.^{1,2,3} Recent hospital-based improvements in discharge care to address some of these challenges, such as medication reconciliation and patient education, have led to reductions in these events.^{4, 5, 6} Yet the patient's perspective about recovery at home remains under-studied and often is missing from policy discussions about improving transition care.

Early studies in transitions research focused on patient and caregiver priorities and unmet needs of older adults for discharge care.^{5, 7} Few studies, however, have explored issues specific to patients with low socioeconomic status^{8,9} and none have focused on a vulnerable, geriatric population in safety net settings. Moreover, many existing interventions have failed to impact outcomes in general populations.¹⁰ Additionally few studies have focused experience of recovery at home *after* discharge^{11,12} and little is known about the challenges to recovery that vulnerable older, socioeconomically disadvantaged adults face at home.

We conducted a patient-centered qualitative study of vulnerable older adults to describe their experience of recovery at home and characterize their needs for a successful transition. Patient perspectives on unmet needs despite hospital-based improvements in discharge care can help inform future interventions to improve outcomes of hospitalization for older adults.

METHODS

Study setting and sample

We conducted a qualitative study of adults (< 55) hospitalized at the San Francisco General Hospital (SFGH) and Trauma Center. Our study was nested within a 700-patient, randomized-controlled trial – the Support from Hospital to Home for Elders (SHHE) study – conducted from July 2010 to July 2013.¹³ Our study focused on patients admitted to a medical service with low income, low health literacy, and/or limited English proficiency (primary language Spanish or Chinese). Briefly, intervention patients received pre-discharge visits with a specialized discharge nurse to develop a personalized discharge plan, and two post-discharge phone calls from a Nurse Practitioner and access to a “warm-line” to answer medical questions. Exclusion criteria included severe cognitive impairment, admission from institutional settings, and not having a working phone number.

To create our sample, we generated weekly lists of discharged patients from February to July, 2012 and invited participation via telephone. We conducted interviews within 30 days of hospital discharge in patients' homes using a discussion guide (Appendix A) informed by recent transitions of care studies.^{4, 7} Participants were given a \$40 gift card. All participants gave informed consent and all research procedures were approved by the IRBs for both the University of California San Francisco and SFGH.

Data collection and analysis—We employed rigorous standards for qualitative research, using the Grounded Theory approach¹⁴ as follows: First, we used the technique of purposeful sampling which is preferred over random sampling in qualitative research to ensure breadth of experience and perspective by age, gender, race/ethnicity, and English proficiency.¹⁵ Second, we conducted all interviews in person: SRG conducted all interviews in English; culturally concordant native speakers performed all interviews in Cantonese/Mandarin (DHC) or Spanish (VG). Third, we continued interviews until we reached theoretical saturation which is the point at which no new ideas emerge from the data.¹⁶ Fourth, all interviews were digitally recorded and transcribed by a professional transcription service and all transcripts were reviewed for accuracy.¹⁷ Fifth, we created an interdisciplinary team with expertise in primary care, hospital medicine, geriatrics, and nursing and held regular team meetings to assess the adequacy and comprehensiveness of all analytic results.¹⁸ Sixth, we developed a code structure iteratively to modify the scope and content of codes as needed; disagreements in coding were resolved through negotiated consensus.¹⁹ Finally, we created an audit trail to enhance the reliability of our findings,²⁰ and used Atlas.ti (version 6.2) to apply the final coding structure uniformly to all transcripts and to retrieve data (quotes) for presentation.

Results

We interviewed a total of 24 older adults within 30 days of discharge to home from the hospital (Table 1). Our final code structure contained 25 codes, from which a recurrent and unifying theme emerged: “missing pieces” in the plan for post-discharge recovery at home. Within this overarching theme, three specific sub-themes emerged describing specific “pieces” or barriers to recovery: (1) functional limitations and difficulty with mobility and

self-care tasks; (2) social isolation and lack of support from family and friends; (3) challenges from poverty and the built environment at home.

Over-arching theme: traditional focuses of care transitions and “missing pieces”

When asked, “tell me how you've been doing since you came home from the hospital,” patients in our study tended to describe traditional medical aspects of post-discharge recovery such as specific instructions about diet, medications, and disease management. Overall, these experiences tended to be positive.

By contrast, when asked specifically “tell me what has been most difficult for you since coming from the hospital,” many patients elaborated on specific issues that had not been addressed during the discharge process or afterward. While these patients understood the medical components of their recovery plan such as medications, they did not feel the plan encompassed how to return to their everyday routines.

“I wish doctors told us more about recovery. Not just drugs...walking is still a problem...and my family is worried because I can't handle things on my own. We didn't know what questions to ask...what sort of things may be good for my recovery.” **63 year-old man (intervention)**

Such experiences helped shape our approach to patients' reports of “missing pieces” in the post-discharge recovery plan. Patients reported a wide variety of missing pieces but, overall, they prioritized 3 specific domains of functional, social, and environmental concerns.

Missing piece 1: functional limitations and difficulty with mobility and self-care tasks

Difficulty at home with mobility, instrumental activities of daily living such as shopping, cooking, or cleaning were among the most common problems reported by patients in our study. Many patients described acute changes in their abilities after discharge.

“Lack of mobility is my problem...it's been a month and I feel like the first day I was discharged...my heart's working well but my body's weak. I can't walk much and I can't lift more than 10 pounds.” **72 year-old woman (control)**

Oftentimes, patients and their caregivers did not realize that function at home would be an issue until they arrived at home. For one patient, this realization occurred just before he returned home but still too late to adjust plans prior to discharge:

“I didn't even think about my stairs until just before my release. I was waiting and I thought, ‘Okay. They're going to get the drugs...I can go home soon.’ Then, all of a sudden I realized, ‘Oh, *&#@! The stairs!’ [Laughter]” **64 year-old man (intervention)**

Other patients described difficulties venturing outside their home after discharge. One patient explained how attempts to resume daily routines such as shopping could deplete needed “reserves” thus interfering with the process of recovery.

“I can't shop like I used to...what took 15 minutes now takes an hour...If you don't have help, you can't build reserves. You're using everything, you can't store

anything up for recovery....my girlfriend helps but you can only ask so much.” **58 year-old man (control)**

Patients rarely described functional issues without also referencing complexities of obtaining or accepting help in the context of their social support system. For many patients, lack of social support compounded the difficulty of both their medical and functional and recovery.

Missing Piece 2: social isolation and lack of support from family and friends

Social support was described as an important component of recovery from hospitalization. Just as many patients described an unanticipated decrease in functional ability after discharge, some also reported they were less able to interact and thus experienced a state of social limitation immediately after discharge.

“I was like in my own little world...I really didn't talk to anybody. It was just not really having the energy or the strength or want to do it.” **63 year-old woman (intervention)**

Even those who had family nearby were not always able to rely on them for support during the period of recovery at home. Some patients reported that even despite best intentions, logistics of transportation and coordinating schedules often proved too difficult to “get it together.”

“Sometimes my daughter doesn't come when she's supposed to...and that gets me depressed...I used to go there every week by bus but I can't do it no more. We just can't get it together.” **56 year-old woman (control)**

Some patients described a shrinking of their social support network due to progressive illness and loss in their functional abilities that resulted in loss of connection with friends.

“Not really any friends visit me...I'm not well enough to get up and do all the things they do so there's no need for them to come around - what do you have in common now?” **57 year-old woman (control)**

Overall, many patients reported that lack of support impaired their efforts to recover from hospitalization and return to the same level of activity they had prior to hospitalization. They noted both missing instrumental help with specific tasks and missing emotional support leading to loneliness and depression. These disadvantages also made it more difficult for many patients to deal with challenges from poverty and their physical environment.

Missing piece 3: challenges from poverty and the built environment at home

Many patients described physical elements of their home environment that were not conducive to recovery. Often, these elements overlapped or interacted with functional and social issues to induce varying degrees of disablement. One patient described a cycle of worsening disease, poverty, and changing physical environments requiring difficult “adjustments.”

“This condition put me on disability: lost my job; lost my place; then shelter... I want to move on but I have to regain a certain level of well-being to adventure out

there, even just to pack. It's about adjustments I haven't been able to make.” **58 year-old man (control)**

While this patient felt that poverty and his changing environment prevented him from regaining his independence and “move on,” patients more commonly described being “stuck” in stable albeit compromising environments extending from their individual homes into the surrounding community. Several patients explained how the inability to move away from these conditions perpetuated a cycle of worsening disease.

“I wish I could move. But what can you do? So many people have gotten asthma from this area and living here isn't making it easier for me to get better.” **57 year-old woman (control)**

Beyond the physical features of their home or community, some patients also described how potent environmental threats to their well-being could be created by the individuals who lived with or around them. One patient living in a Single Room Occupancy hotel described how the shared living environment created an environment of sickness he was unable to escape:

“It's not a good environment... so many sick people. I'm more susceptible to catching things like cold, pneumonia, flu so I try to keep the place clean but it's almost impossible. Here, I'm getting sicker but I don't have the strength to leave.” **64 year-old man (intervention)**

This patient's experience of worsening functional ability in the context of a toxic home environment also illustrates the potential overlap of “missing pieces” in the discharge plan. While functional, social, and environmental problems were not described by all patients, it was uncommon for patients who experienced one of these issues to not be affected by at least one other and, more often than not, these problems were inter-related. This interplay between functional, social, and physical barriers often led to obvious limitations in many patients' abilities to execute specific tasks of recovery from hospitalization at home.

DISCUSSION

Despite recent efforts to improve the discharge process, vulnerable older adults in our study identified several common “missing pieces” after they had returned home. Applying these observations to the classic Disablement Process described by Verbrugge and Jette, such “missing pieces” can be seen as situation-specific disabilities defined as “any gap between personal capability and situational demand.”²¹ While the impact of such disabilities on outcomes such as mortality and independence have been well-documented²² they are often not part of the traditional focus for planning transitions from acute care to recovery at home.

Given considerable variability in the success of hospital-based discharge care through a variety of care transition models,¹⁶ it may be necessary to move beyond traditional aspects of transitions in medical care and focus more on functional, social, and physical barriers.²³ While some have proposed greater emphasis on the “post-discharge environment” to address these issues,²⁴ others have questioned the role of hospitals and scope of hospital-based interventions.^{25,26} Clearly, hospitals cannot fill in all the missing pieces for every patient;

most likely, many of these needs can only be met by the patient's community in partnership with medical community.

Examples of such partnerships are proliferating at national, state, and community levels. Under the Affordable Care Act (ACA), many states are expanding their Medicaid programs which include Home and Community-Based Services that can provide in-home health aides as an alternative to skilled nursing facility placement for patients under 65 with transient or new (hospital-acquired) ADL difficulties.²⁷ On the other hand, not all states are participating in this expansion and many vulnerable patients (including immigrants) will not be eligible for these benefits even if their state participates.²⁸ Also in response to the ACA, initiatives such as the Community-based Care Transition Programs are connecting patients with free or low-cost resources in their community to address difficulties with IADLs including home-delivered meals, transportation, grocery shopping, and home maintenance.²⁹ At the community level, a growing number of cities have developed transition programs to support vulnerable patients with unstable housing,³⁰ often as part of national or federal efforts to address root causes of homelessness. Ultimately, while hospitals may not create or direct programs such as these, they may need to take a stronger role in identifying the most vulnerable hospitalized older adults and matching them to these resources more consistently.

Our results should be interpreted in light of several limitations. First, given the qualitative nature of our study, we cannot assess associations between the missing pieces described here and outcomes such as readmission. Second, our interviews focused on older adults discharged from a public hospital which limits our ability to generalize to other geriatric populations with more resources. Finally, all our participants were enrolled in a clinical trial in which half received specific discharge interventions. We sampled both intervention and control groups but patients not enrolled in this trial may have different transition experiences.

In conclusion, vulnerable older adults in our study identified common “missing pieces” in their plan for transition from hospital to home which may inhibit specific tasks related to recovery from hospitalization. Our findings suggest that hospital-based discharge interventions that focus on traditional recovery tasks such as medications and disease management may overlook social, functional, and environmental aspects of recovery. Home-based interventions to address these “missing pieces” are needed to improve post-discharge recovery for vulnerable older adults.

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APPENDIX A. Support from Hospital to Home for Elders – Patient Interview Guide

“Thank you for talking with me about your health and your recovery at home. I'd like to ask you some specific questions about your experiences and health needs in the days since you left the hospital on (date or “last week”, etc).”

Opening questions

1. How has it been going since you returned home from the hospital?
2. What was most helpful in getting you back home to your normal routine?
3. Do you recall anyone going over your medications before you left the hospital?
4. Did you and your family feel that you were prepared to come home?
5. What aspects of your transition back to home did you feel went particularly well? What aspects did not go so well?
6. After leaving the hospital, did you feel fearful or anxious? What do you think could have reduced your fears?

Questions about specific medical aspects and basic needs of post-discharge care at home

7. Since leaving the hospital, have you had difficulties taking your medications each day?
8. Since leaving the hospital, have you had difficulty with transportation to doctor's visits?
9. Since leaving the hospital, have you received home care from a nurse?
10. Since leaving the hospital, have you had difficulty following the diet your doctor recommended to keep healthy?
11. Since leaving the hospital, have you had problems getting enough food to eat? Have you had difficulty paying other bills such as heating and electricity?
12. Since leaving the hospital, have you or someone who cares for you had difficulty communicating with your doctors, nurses or other providers?
13. Since leaving the hospital, have you or someone who cares for you used the Internet to get help with your recovery?

Questions about specific aspects of social support and post-discharge care at home

14. Who has helped you once you returned home? If multiple people, tell me a little about roles each have played.
15. Let's focus on the person who has helped you most at home – can you tell more about what kind of things they have helped you with?
16. How often does this person help you?

17. What do you think you would do without this person (these persons)?
18. Do you get any help from neighbors or other people living in your community? (e.g. pastor/religious leader, block organizer, sponsor)
19. How important do you think this support has been for helping you recover (get healthy) and stay out of the hospital?
20. How well has the support you've received from friends/family/others met your needs since leaving this hospital?

Questions about more general aspects of social support and community engagement

21. In general, do you have friends, family, or other special people who you can count on to help you when you're in need or when things go wrong?
22. Do you have friends, family, or others who care about your feelings and comfort you?
23. Do you have friends, family, or others who you trust to talk about your problems and help you make important decisions?
24. In general, how often do you see these friends, family or other special people?
25. Do you belong to a church or religious organization? If so, how often did you attend religious services or other activities?
26. Before your recent hospitalization, how often did you get involved with volunteer work or a community organization? (Need some specific examples from communities served by SFGH)

Final questions about specific aspects of social support and post-discharge care at home

27. Can you tell me anything else about problems or difficulties you've had getting better or staying healthy since you left the hospital last time?
28. What things do you think have been most important in keeping you from going back to the hospital? (If readmitted patient: what do you think might have prevented going back?)
29. Is there anything else you think might have helped you stay out of the hospital this time?
30. Is there anything else you'd like to tell me about coming home after leaving the hospital last time?

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Table 1

Participant Characteristics

Characteristic	Total N = 24
Age	Mean: 63 years Range: 55–84 years
Gender	
Men	16 (67%)
Women	8 (33%)
Race/ethnicity	
Black	8 (33%)
White	8 (33%)
Latino	4 (17%)
Asian	4 (17%)
Interview Language	
English	12 (66%)
Chinese	4 (17%)
Spanish	4 (17%)
Total annual household income	
20,000	18 (75%)
>20,000	6 (25%)
Education – last grade completed in school	
0–11 years	5 (21%)
12 years	7 (29%)
>12 years	12 (50%)
Employment status	
Working	2 (8%)
Unemployed or laid off	5 (21%)
Retired	12 (50%)
Other or missing	5 (21%)
Housing situation	
Stable housing	19 (79%)
Unstable or marginal	3 (13%)
Homeless	2 (8%)
Randomized Trial Group *	
Intervention	12 (50%)
Control	12 (50%)

* Intervention patients received a peri-discharge intervention including a pre-discharge visit with a specialized discharge nurse to develop a personalized discharge plan, and two post-discharge phone calls from an NP/PA to assist in the patient's transition to outpatient care.